

Prognosis as Health Trajectory: Educating Patients and Informing the Plan of Care



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J Gen Intern Med 36(7):2125–6

DOI: 10.1007/s11606-020-06505-7

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When clinicians and their patients discuss prognosis, they are usually referring to the “bad news” of a decreased life expectancy associated with such conditions as cancer, heart and lung disease, or dementia. Prognosis, defined as the likely course of a disease or illness, encompasses far more than this. Patients want to know what the future holds for a broad range of conditions and the outcomes associated with those conditions. The astute clinician should always make sure to educate patients on the natural history and likely outcome of a disease or illness, to let them know what they can expect in its course. The designation *doctor*, after all, comes from the Latin word *docere*—to teach.

Nearly 25 years ago, Nicholas Christakis pointed out the lack of formal attention given to prognosis in the field of medicine and the everyday care of patients: textbooks tend to ignore it, medical schools devote little time to it, and physicians prefer to avoid it.¹ Regrettably, not much has changed in the interim in any of these areas. In fact, the extent to which clinicians prognosticate in everyday practice is largely unknown because most research related to prognosis focuses on narrower uses of the term, such as estimates of life expectancy.^{2,3}

Clinicians should broaden their understanding of prognostication beyond the common use of the term to answer the question, “how much time do I have left?” By instead conceptualizing prognostication as an assessment of trajectory—both how has the patient done in the past, and how is the patient likely to do going forward—clinicians will have a tool for promoting patient understanding of illness, informing

conversations about advance care planning, and deciding when re-assessment is needed because the clinical course has deviated from the expected trajectory.² Viewed in terms of trajectories of health and illness and the salient clinical features influencing these trajectories, prognosis readily applies to a wide variety of cases—acute or chronic, simple or complex, self-limited or life-limiting.

This process of prognosticating is critical to the care of a patient. Choosing an appropriate therapy for a condition requires a careful consideration of the health trajectory, which can lead the patient and clinician to consider a much broader set of interventions than medications or non-pharmacologic disease management strategies. Granted, there will always be uncertainty in making clinical predictions. Clinicians can make clear to patients this inherent limitation by providing ballpark estimates, describing alternative scenarios in which things may not unfold as anticipated, and designating time-limited trials for comparing the observed trajectory with the predicted one. The following examples demonstrate how prognosis as health trajectory informs the plan of care across a wide range of clinical scenarios.

One example of using information about the expected course of an illness to guide therapy is in conditions causing short-term impairments in function but with resolution of symptoms within weeks to months. Examples of these conditions include uncomplicated acute low back pain, adhesive capsulitis (frozen shoulder), and the lumbosacral neuropathy seen in patients with diabetes (diabetic amyotrophy).^{4,5} Patients with these conditions—given their natural histories—may not need aggressive interventions. Conservative management, however, requires the patient to understand the likely trajectory of gradual, slow improvement to ease concerns and to shift the focus toward managing functional limitations and symptoms in the interim. For patients with low back pain, one benefit of discussing prognosis is that it serves to counter the “false narrative” that inactivity is necessary and even helpful. The patient’s realistic understanding of the trajectory of low back pain can facilitate well-informed decisions about the resumption of activities and an earlier return to work.⁶

A different approach to communication about the anticipated health trajectory is required at the outset of a new diagnosis of a chronic, progressive condition. For a condition such as dementia, the overall trajectory is one of progressive loss of

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Received August 9, 2020

Accepted December 17, 2020

Published online January 5, 2021

independence and increasing care needs.⁷ Hence, the focus of prognostic discussions for a patient with newly diagnosed dementia should be on ensuring adequate support and providing anticipatory guidance for both patient and caregiver. Prognostic information can be given gradually and iteratively, helping the patient and family accommodate and also giving clinicians time to see the trajectory unfold and hone their information. Initial counseling might include discussions about how the patient can continue to lead a full and satisfying life, along with early-stage recommendations to do estate planning and to consider a safer, more manageable living arrangement. As the patient's illness progresses, conversations might focus on strategies for maintaining independence and quality of life and for reducing caregiver burden. A relevant point to communicate is that the prescription of medication, i.e., a cholinesterase inhibitor, has only a modest effect on the dementia trajectory. Clinicians should think broadly about other factors that can adversely affect cognition and are amenable to intervention, such as visual and hearing impairments, depression, and psychosocial factors including social isolation.

As a final example, when patients with multiple conditions have an acute illness or event, prognostication generally requires a consideration of the often-complex interplay of factors influencing the health trajectory of these patients. Clinicians should seek as much as possible to piece together a story of their patients' health leading up to, involving, and following an acute illness or event. Understanding the trajectory up to the present then allows clinicians to anticipate where their patients are headed and whether interventions may alter that trajectory. For a patient with several chronic conditions and a decline in mobility after a recent hospitalization for pneumonia, it is important to determine the timing of and likely contributors to the decline in mobility. Is this simply a case of deconditioning from immobilization during the hospital stay, or were other factors involved, such as weight loss or cognitive impairment? Looking ahead, physical therapy alone is unlikely to restore a patient's mobility if there are additional contributing factors of weight loss from poor dietary intake and difficulty in preparing food because of cognitive impairment; however, a combined approach of physical therapy, dietary supplementation, and the close involvement of a caregiver would have a much greater chance of success. Appreciating the multiple contributors to the patient's decline allows for more individualized prognostication and a more effective plan of care.

When clinicians focus on the health trajectories of their patients, they become expert observers of these trajectories. They should note carefully year-to-year and month-to-month changes in their patients' status and utilize this information to

refine their predictions of both short- and long-term outcomes. While we acknowledge the challenges involved in asking busy clinicians to take on additional tasks, we believe that many clinicians are already making these observations. Innovative use of the electronic medical record, already a source of many clinical reminders, would be to prompt clinicians to share their observations with patients with the recording of new diagnoses or changes in clinical status. These predictions may lead to further diagnostic evaluation, in response to the observation that a trajectory does not fit the expected pattern. Alternatively, these predictions may lead to a decision not to pursue further evaluation, in the context of an inexorable downward trajectory. In all cases, this broad approach to prognostication becomes a key feature of everyday clinical practice and the field of medicine overall.

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Funding This study was financially supported by the Claude D. Pepper Center, National Institute on Aging P30 AG21342 and the National Institute of Nursing Research R01 NR016007.

Compliance with Ethical Standards:

Conflict of Interest: The authors declare that they do not have a conflict of interest.

Prior Presentations: None

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